#### **MEETING SUMMARY**

# ILLINOIS DEPARTMENT OF PUBLIC HEALTH ALZHEIMER'S DISEASE ADVISORY COMMITTEE (ADAC) MEETING April 15, 2019 11:00 a.m. to 3:00 p.m.

Approved October 28, 2019

Memorial Center for Learning and Innovation (MCLI)
Schnirring Board Room MCLI 2E
228 W. Miller Street
Springfield, IL 62702
WebEx was available to those unable to attend in-person

#### Welcome

- Jennifer thanked Southern Illinois University School of Medicine, Memorial Center for Learning and Innovation, and Memorial Health System for hosting the meeting and providing lunch.
- New appointed members were introduced and invited to share information about themselves. A list of current vacancies was shared.
- This was the first ADAC meeting to offer WebEx capabilities for those unable to join by phone. An overview of WebEx was provided.

#### Introductions

- Appointed/Pending Members Present: Tom Ala, Rollin Barton (proxy for Phyllis Roate), Jen Belkov, Evan
  Davis, Nancy Flowers, Jeannine Forrest, Susan Helm, Shana Lister, Carol Mauck, Jennifer Martin, Marsel
  Mesulam, Conny Moody, Darby Morhardt, Teresa Parks (proxy for Mary Milano), Beth Phelps, and Raj Shah.
- Guests Present: Michelle D, Kara Helton, Colette Jordan, Greg Kyrouac, Barbara Sittler, and Bob Struble.
- Appointed/Pending Members Absent: Cindy DeGroot, Orlinda Speckhart, Jeff Christiansen, Sam Hill, Lori Kerns, Kathleen Knope, and Melvin Siegel.

### Review and Approval of October 22, 2018 Meeting Minutes

• Copies of the minutes were distributed prior to the meeting and available at the meeting. Evan motioned for the approval of the minutes, with a second from Raj. Minor edits were made. Motion carried.

# Discussion of State Strategic Plan Revisions

- The Alzheimer's Disease state plan is updated every three years. The last plan was released in December 2016, so the next plan will be due December 2019.
- Update from the ad hoc committee
  - Members of the ad hoc committee were introduced. An overview of the progress made since the last ADAC meeting was shared. The committee was formed in October 2018. They reviewed the current plan, identified areas to update, and assigned authors for each section. A survey was created and distributed to ADAC members and stakeholders to provide input on the short- and long-term recommendations. The ad hoc committee met regularly to review the survey results and edits from authors.
  - From April to October 2019, the ad hoc committee will continue to review edits to the plan and present a final draft for ADAC's review and approval during the ADAC meeting on October 28. Then the plan will be reviewed internally by IDPH. The goal is to release the plan by the first of the year.
  - Review suggested revisions to the plan, the short- and long-term recommendations
    - The draft strategic plan shared during today's meeting reflects the proposed revisions to the recommendations and edits to the plan.
    - As a group, members reviewed and approved edits in the plan except for the short- and longterm recommendations, which were reviewed separately. Some of the key edits included:

- Members were asked to share feedback and edits to the following sections: Overview, Legislative History, Alzheimer's Disease Definition, Opportunities and Challenges, etc.
- Discussion was held around opportunities and challenges over the last three years which needed to be included in the plan.
- Data within the report will be updated once the Alzheimer's Associations' "Facts and Figures" document is released.
- Members were asked to verify their information displayed in the plan.
- A recap of the original recommendations and the efforts to prioritize them were provided. The proposed revised recommendations were displayed during the meeting for members to review and individually vote if they approved, approved with recommendations, neutral or disagreed. Members discussed the revisions which members either approved with recommendations or disagreed.
- A member asked if public hearings on the strategic plan are required. Jennifer B will explore.
- The approved edits will be made to the strategic plan. The ad hoc committee will continue to meet regularly to monitor the progress of the plan's revisions.

# Update on Alzheimer Disease Research Funds (ADRF)

• It is estimated there will be \$194,000 available going into FY20. The deadline for applications was Friday. IDPH received four applications. Staff will conduct the Tier 1 review tomorrow and the Peer Review Panel (Tier 2 review) will occur on May 13. A meeting will be set for ADAC (Tier 3 review) to review ADRF FY20 applications. A doodle poll was sent to members prior to the meeting to identify dates in early or mid-June to conduct the Tier 3 review.

# ➤ Illinois Updates – Regional Alzheimer Disease Research Centers

- Rush University (Raj)— defer to Illinois Cognitive Resource Network (ICRN) update.
- Northwestern University (Darby) –25<sup>th</sup> Annual Alzheimer's Day will be Thursday, May 9, 2019. Dr. Eric Reiman will be the keynote speaker. The event will include poster sessions showcasing research on aging and dementia. The afternoon will focus on "Music, the Arts and Human Experience"
- Southern Illinois University (Tom) pleased to have funding reinstated. The center is rebuilding their programs. They will be recruiting a new director. Their memory conferences will be in early May. One will be for professionals; the other for the community. Their Taking Alzheimer's Care Beyond the Medical Center program, includes art, music, exercise, education, and storytelling for caregivers. Their grant from Illinois Department on Aging will end in September. One of the pilot programs implemented the evidence-based program called Stepping Up and added dance to the program. To continue the replication, they will do a training in Springfield on May 15 and 16.

# Illinois Updates - State Agency Updates

- Illinois Department on Aging (Rollin) Rollin reported Phyllis Roate will provide an update.
- Illinois Department of Healthcare and Family Services (Kara) Kara is the coordinator for the Supportive Living Program, a home and community-based services waiver program. The program is similar to IDPH's assisted living program. It is different in that Medicaid moneys are allowed to be used for services. They have private pay residents as well (approximately 40% of residents are private pay). Out of their 152 operational buildings, five are dementia sites. They are allowed to have alarmed delayed exit doors as a safety intervention. Residents have to be screened and verified to meet that safety intervention before they can be placed in that unit. They also accepted a round of applications. Around 50 applications were received. There was a good distribution across the state. They are finalizing those reviews. They anticipate making announcements in mid- to late-May. They will provide an update at the fall ADAC meeting.
- Illinois Guardianship and Advocacy Commission (Teresa) Their website posted an updated version of their guardianship training should families have questions about their role as a legal guardian <a href="https://www2.illinois.gov/sites/gac/OSG/Pages/Guardianship-Training.aspx">https://www2.illinois.gov/sites/gac/OSG/Pages/Guardianship-Training.aspx</a>. They are a co-sponsor of

the Illinois Guardianship Association conference on May 7 in Springfield. The conference is open to the public. Topics include guardian decision making, end of life decision making, advance directive and presentations on Medicaid updates and other disability related services. They continue to provide adult guardianship services. They testified on HB0344, legislation on electronic monitoring.

## ➤ Illinois Updates - Illinois Cognitive Resource Network (ICRN) Update

- Raj shared three brief updates:
  - ICRN is an individual helping them with communications to post messages and resources on their website https://ilbrainhealth.org/ so people can access and use them.
  - ICRN provides state technical assistance for two national programs Dementia Friendly Communities and Dementia Friends. Dementia Friends is a lay person activity where people can sign up to show support for individuals in their community who have dementia and their caregivers. There is around 2,000 enrolled in Illinois. They have been hosting webinars to train individuals to become Dementia Friends champions so they can provide presentations in their communities. Individuals also can complete modules online to be trained to provide presentations.
  - Dementia Friendly America efforts in Illinois are increasing, especially due to the work done by the local area agencies on aging. Evanston was one of the first communities to go through the new process. River Forrest, Lake County, Chicago, and Kankakee County have become a Dementia Friendly Community. Other communities working towards becoming a Dementia Friendly Community are Glencoe, Oswego, and Elgin.

### Other ADAC Discussion

- Tom requested an update on SB1726 which could impact ADAC. Jen B introduced legislation which would change the membership of ADAC as well as change the way the tax-check off is used. Funds would support a dementia coordinator and modules on the Behavioral Risk Factor Surveillance System. The bill passed the Senate last week and was moved to the House. They will be lobbying it on Lobby Day on May 1.
- Jen B report the American Association of Retired Persons introduced SB1510 to address facilities not staff correctly. It would implement automatic fines based on 2010 legislation. It also addresses the overuse of psychotropic drugs. Several organizations are working together on this legislation.
- Collette shared the agencies on aging are piloting Stress-Busting for Family Caregivers. The initiative was started in north Chicago and Kankakee. The program was well-received. A train-the-trainer was offered last June which fifteen facilitators were trained in the region. Now, they will be expanded across the state. Another train-the-trainer will be helped in DuPage County on August 29-30.
- Jeannine is working with the Dementia Society of America to provide a free monthly webinar called
  Dementia Unplugged. It is open to any family, caregivers, or professional caregiver. Webinars are
  archived. Jeannine also is offering leadership training skills for executives and other management team
  members in long-term care who have not had the benefit of learning how to be managers and working
  together in group settings.
- > Reminder of Fall meeting October 28, 2017 from 12-3 at Northwestern University in Chicago.